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TB and TB-HIV care for adolescents and young adults

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SUMMARY

SETTING: Nine high-burden public tuberculosis (TB) clinics in Gaborone, Botswana.

OBJECTIVE: To evaluate the challenges encountered, healthcare worker (HCW) approaches, and supported interventions in TB and TB-HIV (human immunodeficiency virus) care for adolescents and young adults (AYA, aged 10–24 years).

DESIGN: Semi-structured interviews with HCW in TB clinics, analyzed using thematic analysis.

RESULTS: Sixteen HCWs were interviewed. AYA developmental needs included reliance on family support for care, increasing autonomy, attending school or work, building trust in HCWs, and intensive TB education and adherence support. Stigma strongly influenced care engagement, including clinic attendance and HIV testing. Health system barriers to optimal AYA TB care included limited staffing and resources to follow-up or support. HCWs utilized intensive education and counseling, and transitioned AYA to community-based directly observed therapy whenever feasible. HCWs supported implementation of youth-friendly services, such as AYA-friendly

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spaces or clinic days, training in AYA care, use of mobile applications, and peer support interventions, in addition to health system strengthening.

CONCLUSION: HCWs utilize dedicated approaches for AYA with TB, but have limited time and resources for optimal care. They identified several strategies likely to improve care and better retain AYAs in TB treatment. Further work is needed to study interventions to improve AYA TB care and outcomes.

RÉSUMÉ

Neuf dispensaires tuberculose (TB) très chargés à Gaborone, Botswana.

Evaluer les defies rencontrés, les approches des travailleurs de santé (HCW) et les interventions soutenues en matière de TB et de prise en charge TB-VIH (virus de l'immunodéficience humaine) pour les adolescents et les jeunes adultes (AYA, âge 10–24 ans).

Entretiens semi structurés avec des HCW dans des dispensaires TB analyses par analyse thématique.

Seize HCW ont été interviewés. Les aides au développement des AYA ont inclus le soutien familial en matière de traitement, une autonomie accrue, le fait de frequenter l'école ou de travailler, d'avoir confiance dans les HCW, et une education TB intensive et un soutienà l'observance. La stigmatisation a fortement influencé l'engagement dans le traitement, notamment la frequentation du dispensaire et le test VIH. Les obstacles à la prise en charge optimale des AYA en matière de TB, lies au système de santé, ont inclus la pénurie de personnel et de ressources pour suivre ou soutenir les AYA. Les HCW ont utilisé l' èducation intensive et le conseil et ont transféré les AYA vers le traitement directement observé communautaire chaque fois que c'était possible. Les HCW ont soutenu la mise en œuvre de services conviviaux pour les jeunes, comme par exemple des espaces ou des journées de dispensaire dédiés aux AYA, une formationà la prise en charge des AYA, le recoursà des applications sur mobile età des interventions de soutien par les pairs, en plus du renforcement du système de santé.

Les HCW utilisent des approches dédiées aux AYA en matière de TB, mais ils manquent de temps et de ressources pour une prise en charge optimale. Ils ont identifié plusieurs strategies susceptibles d'améliorer le traitement et de mieux retenir les AYA en traitement de TB. Davantage de travail est nécessaire pour étudier les interventions visant á améliorer la prise en charge de la TB des AYA et leurs résultats.

RESUMEN

Nueve consultorios públicos con alta carga de morbilidad por tuberculosis (TB) en Gaborone, Botswana.

Evaluar las dificultades encontradas, las estrategias de los profesionales de salud (HCW) y las intervenciones respaldadas de atención de la TB y la coinfección TB-VIH (virus de inmunodeficiencia humana) en los adolescentes y los adultos jóvenes (AYA) de 10–24 años.

Análisis temático de las entrevistas semiestructuradas a los HCW, realizadas en los consultorios de TB.

Se entrevistaron 16 HCW. Entre las necesidades de desarrollo de los AYA se encontraron la dependencia del apoyo familiar a la atención, la autonomía progresiva, su asistencia a la escuela o

el trabajo, la creación de un clima de confianza con los HCW y las actividades intensas de educación sobre la TB y apoyo a la adhesión al tratamiento. La estigmatización influyó de manera considerable en la participación en la atención, incluida la asistencia al consultorio y la realizacién ´de la prueba del VIH. Fueron obstáculos del sistema de salud a una atención optima de la TB en los AYA, la escasez de personal y de recursos dedicados al seguimiento o al apoyo de los jóvenes. Los HCW practicaban de manera intensa la educación y la orientación y dirigían los AYA hacia el tratamiento bajo observación directa en la comunidad, siempre que era posible. Los HCW respaldaron la introducción de servicios atentos a las necesidades de los jóvenes, como los espacios o los días de consulta dedicados a los AYA, la capacitación sobre una atención adaptada a este grupo de edad, el uso de aplicaciones para móviles y las intervenciones de apoyo entre pares, además del fortalecimiento del sistema de salud.

Los HCW utilizan enfoques adaptados a los AYA con TB, pero cuentan con poco tiempo y escasos recursos para prestar una atención óptima. Estos profesionales definieron varias estrategias que pueden mejorar la atención y aumentar la retención de este grupo en el tratamiento de la TB. Se precisan nuevos estudios que analicen las intervenciones encaminadas a mejorar la atención de los AYA con TB y sus desenlaces.

Keywords

adolescent; HIV; linkage to care; retention; youth-friendly care

THE GLOBAL BURDEN of tuberculosis (TB) among adolescents and young adults (AYA, aged 10–24 years) was estimated at 1.78 million in 2012, equivalent to 17% of all new TB cases.[1] AYAs are at increased risk for TB exposure and disease, and cases may not be adequately captured through passive case-finding.[2–4] Importantly, AYAs with TB have particular management challenges and clinical features requiring tailored approaches.[5–7] AYAs have specific needs and barriers to healthcare engagement, particularly for diseases requiring prolonged or chronic treatment.[8] For the highly complex and stigmatized conditions of TB and TB and human immunodeficiency virus (HIV) coinfection, which require sustained adherence and retention in treatment, AYAs are at risk for poor outcomes; however, AYA-specific approaches to TB care are yet to been delineated.

Studies in Botswana and South Africa have demonstrated increased risk of loss to follow-up (LTFU) among AYAs with TB, particularly for TB HIV coinfection.[6,7,9] LTFU from TB treatment may lead to poor clinical outcomes, ongoing TB transmission and drug resistance.[10] LTFU among TB-HIV-coinfected AYAs likely reflects compounded challenges of TB-HIV care, coping with stigma and mental health challenges, financial burden of treatment and limited social support.[11,12] Challenges faced by AYAs living with HIV are well-described, including difficulties related to HIV disclosure, psychosocial challenges, antiretroviral adherence and transitions in care.[13,14] Far less is known about the challenges for AYAs navigating care for TB or TB-HIV coinfection.

Although they represent a quarter of the world's population, and investments in AYA health pay dividends across the life course, AYAs have traditionally been neglected in global public health.[15] The World Health Organization (WHO) defined youth-friendly services in 2002,

centering on accessibility, acceptability, equitability, appropriateness and effectiveness.[16] Since then, there has been increasing implementation of youth-centered approaches to healthcare,[17,18] notably in the provision of HIV treatment.[19–23] Meanwhile, although TB is a leading cause of morbidity and mortality among AYAs, youth-centered approaches to TB care have largely not been addressed.

In this qualitative study, we investigated healthcare worker (HCW) perspectives on AYA-specific needs and challenges in TB and TB-HIV care. This included HCW approaches to dealing with these challenges, and the need for youth-centered approaches to support AYA TB care in Gaborone, Botswana (a high TB and HIV burden setting).

METHODS

Setting

HCWs were recruited at nine public primary care clinics in Gaborone, Botswana, which had been noted to have increased LFTU among AYAs.[6,10] These clinics treat the majority of TB patients in Gaborone.

Study population and procedures

HCWs were recruited at each clinic if they regularly treated TB patients, and if they had experience managing AYAs with TB.

A semi-structured interview guide was developed around the research questions. Open-ended questions were used to investigate perceived youth-specific challenges in TB and TB-HIV care, including examples, current approaches in management, and perspectives on interventions required to improve care. Interviews were conducted between June and August 2016 in English by trained researchers (LAE and JE). Responses were audio-recorded and transcribed. Transcripts did not contain identifying information. Minimal demographic data were recorded to protect the identity of respondents.

Analysis

Preliminary codes and a codebook using three transcripts with rich narratives were established collaboratively by multiple members of the study team (LAE, EDL, JE, SA). The codebook included definitions and examples from the texts. Codes were organized into a hierarchy according to the research questions, using a Social Determinants of Health Model incorporating adolescent developmental concerns in healthcare.[8,24] After coding several transcripts and establishing inter-rater reliability and consensus, transcripts were coded independently by three team members (LAE, JE, and SA; LAE coded all transcripts; each transcript was coded by two or three team members) using NVivo v12 (QSR International, Burlington, VT, USA). Transcripts were analyzed concurrently with ongoing interviews to assess probing and preliminary themes. Interviews continued until thematic saturation was reached; between one and three HCWs were interviewed at each site. Coded excerpts were analyzed and discussed, with attention to both commonly shared and contrasting HCW perspectives. Overarching themes emerged and were agreed upon through discussion and consensus of all team members.

Demographic characteristics were summarized through standard descriptive statistics using Stata v14.1 (StataCorp, College Station, TX, USA).

Ethics

The study was approved by the Health Research and Development Committee, Botswana Ministry of Health, Gaborone, Botswana, and the Institutional Review Board of the University of Pennsylvania, Philadelphia, PA, USA. Each participant provided informed consent. Consent procedures included assurances that neither participation nor the content of confidential interviews would have any bearing on employment or otherwise affect professional status.

RESULTS

Interviews were conducted with a total of 16 HCWs (Table 1). The majority (13/16, 81.25%) were aged 25–34 years, were female (12/16, 75.0%), and held a diploma in nursing (11/16, 68.8%). There was wide variation in their experience in treating TB patients, ranging from 0.2 to 17 years (median, 4).

Major themes emerged in rich narratives from HCW interviews. These are presented with illustrative excerpts and discussed below.

AYA-specific needs and challenges in TB and TB-HIV care

HCWs observed multiple AYA-specific developmental needs that influenced their TB management (Table 2). Needs were heterogeneous, varying with patient age, development and circumstances. AYAs have some level of reliance on family members and others, while throughout adolescence they are developing autonomy and self-reliance. As such, HCWs reported that family support played a major role in AYA TB care. When that support was lacking (e.g., due to a lack of caregiver understanding about TB, severe poverty, family conflict or neglect) AYAs faced major challenges to their adherence or follow-up in care. HCWs reported particular challenges managing older AYAs who had left home and AYAs presenting without a caregiver to clinic. For these older AYAs, community-based directly observed therapy (DOT) was not feasible when an appropriate support person could not be identified.

Stigma, which they mentioned is a barrier for many patients in TB and HIV clinics, was seen as a particularly important factor leading to AYA LTFU from TB or TB-HIV care. HCWs described AYA as frequently anticipating stigma if they were seen at a TB clinic. They noted that AYAs did not want to wait at the clinic, both because of their needs to attend school or work, but also because they did not want to be seen there. Furthermore, stigma resulted in AYA hesitance and delays in testing for HIV, and in seeking HIV treatment when needed. HIV testing is routinely recommended for patients receiving TB treatment in Botswana, but typically requires that the patient seek HIV testing outside of the TB treatment area. TB and HIV treatment are also not routinely co-located.

Several systemic challenges adversely affected AYA TB care, including poverty and financial challenges at the level of the family or community. Pervasive alcohol use in the

community was also commonly reported as a barrier to AYA care. Healthcare system challenges were prominent, including understaffing of clinics, such that HCWs did not feel that they had sufficient time for the intensive counseling or follow-up that is especially important for AYA patients. Some clinics lacked access to transportation to perform home visits. HCWs described using their personal mobile phones for follow-up communication to maintain AYA in care.

HCWs described particular challenges related to AYA mobility and migration. School and work conflicts are also commonly challenging even for those AYAs with geographic stability. HCWs noted that these challenges are often more complicated among AYAs than among other age groups.

HCWs described developmental differences in communication with AYAs. This included the need for AYAs to have more intensive education or counseling, as well as the need to avoid judgment and ensure confidentiality in care. The development of a respectful, trusting relationship between AYAs and their HCWs was seen as critical to ensuring AYA adherence to care.

HCW approaches to AYA TB and TB-HIV care

Some HCWs initially commented they use the same approach with AYAs as for older adults with TB. Indeed, dedicated guidance or management approaches for AYA do not exist under the Botswana National TB Programme (NTP), as is generally the case for TB programs globally. However, in the course of our interviews, several specific approaches that HCWs utilize with AYAs emerged (Table 3).

HCWs adapt TB care to AYAs in several ways. For example, they flexibly adjust visit times to accommodate AYA schedules. They liaise with family members as treatment partners, provide more intensive counseling and adherence support for AYAs, and adapt their communication styles to build rapport and trust, including using texting communications preferred by AYAs. HCWs transitioned AYAs to community-based DOT whenever a family member or community health worker was available to monitor adherence. This allowed AYAs to more reliably adhere to care despite their busy schedules and anticipated stigma. For AYAs who were lost to follow-up, HCWs performed home visits where possible (many clinics lacked transportation or staff for this).

Necessary interventions to support AYA TB and TB-HIV care

While HCWs strived for youth-friendly TB care, they recognized that they had limited resources to facilitate such care. They discussed that AYA TB care could be more optimally delivered with the help of key interventions (Table 4).

Community-based DOT was widely supported for AYAs, and seen as a facilitator to adherence and retention when there is a reliable caregiver or support person to perform DOT. However, for those lacking such a person, other solutions are needed. Community HCWs through local organizations may provide DOT, but this was not available at all sites. Having a consistent means of providing community-based DOT was widely endorsed.

Similarly, HCWs commonly raised a need for resources to conduct home visits for AYAs. This was seen as crucial to ensure re-engagement for AYAs lost to follow-up. Clinic staffing and transportation limitations often prohibit the provision of community outreach by HCWs. Home visit capacity is limited, but when available was said to improve AYA-friendly care and reduce LTFU.

When asked how AYA could be optimally supported in TB care, nearly every HCW independently suggested that a range of youth-friendly services would be helpful. These included youth-friendly clinics or spaces; staff with training in youth-friendly care; and resources for intensive counseling, adherence, and mental health support. While alcohol abuse was a recognized challenge among AYAs and others, HCWs lacked a dedicated program or training for managing alcohol abuse. Some HCWs considered whether use of mobile apps or social media could help facilitate communication with AYA. Finally, many HCWs sought greater resources to help AYAs struggling with food insecurity or poverty.

Several HCWs desired peer support groups for AYAs with TB. They had observed the benefits of AYA support groups for HIV and considered ways that such models could be adapted to TB care. Peer groups were seen as facilitating education and breaking through isolation and stigma.

Importantly, many HCWs discussed ways that the introduction of interventions to support AYA TB care could simultaneously strengthen other aspects of TB-HIV care cascades. For example, having a vehicle and/or additional staff for home visits could also support education and counseling, community-based DOT, contact-tracing and active case-finding in these same homes and communities. In addition, implementing youth-friendly services could improve adolescent knowledge about TB and detection of TB in this age group, an important focus for NTPs. Many HCWs expressed that while working with AYAs could be challenging, it was a rewarding aspect of their role: ‘It’s exciting to work with adolescents’ (25–29-year-old, female); ‘You know young people, they are so full of life’ (30–34-year-old, female).

DISCUSSION

While there is emerging literature and broad support around youth-friendly services for HIV care,[25–27] there is little to no scientific literature on youth-friendly approaches in TB care. In this study, HCWs identified multiple AYA-specific needs and challenges that impact TB care. Working from key themes that emerged from this study, and considering the developing literature around youth-friendly services, we propose several areas that may warrant consideration for strengthening AYA TB and TB-HIV care (Table 5).

Noting the benefits seen for AYAs with HIV engaged in peer groups,[25–27] HCWs in this study considered how to implement peer support programs for AYAs with TB. While TB is not a life-long condition, it is heavily stigmatized,[28] entails a prolonged treatment course, and depends on excellent adherence to treatment. Strategies to implement peer support in TB care might include linkage to a peer mentor with a history of TB, attendance at group education sessions, or remotely connecting AYAs in TB care through texting or private

social media groups. The use of these technologic approaches could allow AYAs with TB to be connected across broad geographic areas.

We found that while HCWs individually sought to adapt youth-friendly approaches, they recognized a need for formal training or expertise in this area. National or international guidelines for providing youth-friendly TB care have not been developed, leading to each HCW to adapt to these challenges without a support framework. Introducing HCW training for youth-friendly TB care, while establishing context-specific guidelines, would provide HCWs with improved skills and standardized resources to address the age- and development-specific challenges influencing AYA adherence and engagement in TB care. HCWs favored providing youth-dedicated clinic spaces or times, perceiving that AYAs may more readily access care in such settings.

Some health system strengthening interventions may particularly benefit AYAs who require intensive support. These include increasing HCW capacity to manage TB patients through increased staffing, implementation of clinic navigators, or provision of resources to improve follow-up or comprehensive care of TB patients.

AYAs with TB may also particularly benefit from novel interventions such as smartphone-based video-observed therapy (VOT).[29] Strategies for implementing and studying VOT in this group should be considered. Texting interventions may also be considered to help support communication with AYAs in TB care.

In this study, we evaluated HCW perspectives on AYA-specific needs, challenges, and approaches in TB care. A major limitation is that we were unable to include interviews with AYAs themselves. Qualitative work with AYAs would allow direct assessment of the challenges and unmet needs in care from their own perspectives, and this is an important area for further study. Nevertheless, the current study of HCWs emphasizes specific aspects of caring for AYAs with TB, including experiences, challenges, and HCW-proposed AYA-specific approaches, which have not previously been explored and which merit study in their own right. Indeed, HCWs who regularly engage in this challenge shared thoughtful reflections on how to improve AYA TB care.

As qualitative researchers, we must additionally consider the potential role of our own bias in the collection and analyses of interviews. Interviews were conducted by English-speaking researchers from the United States. It is possible that respondents may have shared different information with local researchers. Finally, while we informed HCWs that their participation or responses would not impact their position or status, it is possible that some participants may not have shared specific challenges with us. For example, they may have felt compelled to present an ideal of clinic practices and experiences, or that there could be consequences to discussing negative experiences or outcomes. We tried to minimize bias by involving key members of the Botswana NTP and of the Gaborone District TB leadership in the design of our study and interpretation of findings. Our interview guide was also informed by extensive literature review and previous experience in adolescent TB and HIV care in Botswana.

Interviewees expressed the idea that AYAs themselves have untapped potential to support work against TB, including through peer support and education interventions. Such youth

peer-support interventions are currently lacking for TB care. Strategies to implement and study such programs should be explored. Strengthening the AYA TB and TB-HIV care cascades in this way is likely to benefit individual AYAs, but also to improve TB control in the wider community.

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Table 1

Characteristics of healthcare workers who participated in key informant interviews

Characteristic	*n* (%)
Age, years	
25–29	8 (50.0)
30–34	5 (31.3)
35–39	2 (12.5)
40–44	1 (6.3)
Female sex	12 (75.0)
Years treating TB patients, median [IQR]	4 [1.3–9.0]
Educational degree	
Diploma in Nursing	11 (68.8)
Bachelor's Degree in Nursing	4 (25.0)
Not ascertained	1 (6.3)
Clinic site	
Bontleng	1 (6.3)
Broadhurst 3	3 (18.8)
Extension 2	2 (12.5)
Gaborone West	1 (6.3)
Lesirane	1 (6.3)
Mogoditshane	1 (6.3)
Nkoyaphiri	2 (12.5)
Old Naledi	2 (12.5)
Phase 2	3 (18.8)
Total, *n*	16

TB = tuberculosis; IQR = interquartile range.

Table 2

AYA-specific needs and challenges in TB and TB-HIV care: themes emerging from interviews with HCWs

Major themes	Example excerpts
AYA-specific needs in TB and TB-HIV care	
AYA needs to attend school or work	'Most of the adolescents they are schooling, so they can't manage treatment and schooling at the same time. So, it's difficult on their side. Most [schools] in Botswana, most of the schools they [do not have] clinics. …They have to come to doctor's appointments and then go back to school. So it's difficult on their side.' (25–29-year-old, male)
AYA mobility and migration	'There's so much migration among the adolescents. …you leave, you'd have found a job after a few weeks, you leave this one, you look for a better one maybe. Or you have no contract work. There's no money to pay rent. You move back at home because you can't stay without paying rent like that. Maybe there's an emergency, you lose the job without even expecting [it], then you move home. You can't even think straight, you even forget. You'll remember when you get there— …my supply.' You go to the nearest clinic and they'll say, 'ah, you're not registered here, you should go back to where you've been registered initially.' I think it's common. Even adolescents like here, they'll come to Gaborone for studies, then maybe after studies they find a guy, they date, they cohabit. From there, the guy doesn't want them anymore. They go back home, leaving everything this side. They just go. I think it's common among the adolescents.' (25–29-year-old, female)
Needs for more intensive education or counseling	'They are difficult to open up. Like that lady whom I was talking about [with poor adherence]. To me I think there was an underlying cause [for] why she's behaving like that. But, I don't know, maybe she wanted the time you sit with her, she will open up, because most of them we take into a 'sweetheart, what is your problem?… Your mother saying you went on Friday, you came on Monday, and you didn't even take the tablets for the weekend. What was your problem?' She will be saying, 'no I don't have any problem.' But, there is a problem. Maybe the problem is the issues of the boyfriend. It has not been disclosed that I'm taking ARV and TB [treatment], so if I go with the drugs the boyfriend will see that I'm very sick I'm going to give a disease, you see. Maybe there were some of those underlying problems. You need to dig more.' (30–34-year-old, female)
	'But, the good thing is that, even as a nurse, when you are working with them, they have to be convinced that even the information that we are giving them, it's very well-researched, timely information, because you don't [want] to give them information that is contradicting. Because if I can tell them something and another nurse will tell them something [else], they won't agree. Sometimes, they will opt to wait for me, so that, 'ok if [name]'s not there, then you are not going to do any change.' Because I will give them information and encourage them to question me if they don't understand or if they see I am doing something that is different from what I told them. So if they question you, and you don't answer convincingly, now you have a problem. It makes them difficult to deal with different [HCW]. Well, it's like now their trust is entrusted in one person.' (30–34-year-old, male)
Freedom from judgment	'They [AYA] are different, they want us to be friendly …and to show them that we don't judge them, we accept them as any other person… They want us to make them feel free, you see. That's when they can be able to come here everyday. But when the environment is not friendly, I don't think they will come for the tablets.' (30–34-year-old, male)
Growing up in the 'information age'	'They know a lot. They hear a lot. They search a lot. Because some of them, they come with this reading information they have heard from the Internet or from their friends. But adults (laughs), adults, adults, some of them, they…they just agree with everything that the HCW say (laughs). With the adolescents, they read a lot. They can even know much more than you yourself will know as a HCW. They know a lot. They question each and every, every little thing. They question. Most of them they question. They won't just accept everything that you're telling them. You have to explain. It's a good thing.' (25–29-year-old, female)
Confidentiality in care	'They need more confidentiality. So, they have to trust that the information that you have [is] only between you and them, because they don't want to be stigmatized. That's [what] I've observed. And in most cases, we discuss things when it's me and the client [alone]. That's when they become more and more comfortable.' (30–34-year-old, male)
Need for family support	'Well, with [young adolescents], they're normally supported by parents. …that age from 17–24, normally they just abscond treatment. They come to the clinic; they are sick by that time. And those symptoms they'll disappear because of the treatment they're taking. Now they're feeling better after those things; they can just disappear.' (30–34-year-old, male)
	'I think most of the counseling is being done with the parent. How should they support this child at home? …But if you don't have support, that's the problem that you can have. Maybe the guy's staying alone here because most of them here, around 20–24, you find they're not staying with parents now. …They are staying alone. Maybe somebody is coming from far to come look for a job here.' (30–34-year-old, male)
AYA-specific challenges in TB and TB-HIV care	
Poverty or financial challenges	'Some [AYA] will say they don't have money for transport every day. Some will say they don't have food so they can't take treatment without eating. Those sorts of things.' (30–34-year-old, female)

Major themes	Example excerpts
	‘Those ones who go to school, they have to pay their rent and buy food and also transport; they don’t eat well. They need food. …Most of them will complain of not having enough food.’ (30–34-year-old, female)
Family conflict or abuse	‘He was on TB treatment. He was taking ART. It was a retreatment case. He was taking even the injections. I think there were some problems at home, because he’s an orphan. So, he did not come [to clinic]. We tried to talk to him. Then, we managed with him coming forward to go and isolate him at [a hospital]. That’s where he finished the treatment. Because he had usually come here complaining that at home, they’re not treating him well. Because he was just an orphan. He was the one who suggested that he be kept in a hospital, where he will take the injections and the tablets.’ (35–39-year-old, female)
Stigma	‘Most [AYA] they don’t want people to know that they have TB. When you talk of TB, they think of HIV.’ (35–39-year-old, female)
	‘What are you doing every day in the clinic?’ You can’t tell a friend what you’re doing at the clinic. Now, here, the best way is to abscond treatment, so that they won’t see you at the clinic. I think that’s the problem there.’ (30–34-year-old, male)
	‘My experience is: young patients, they are difficult to manage. …Most of them they don’t come for follow-ups. Most of them they are afraid of stigma and discrimination. Most of them they are schooling so in this case of schooling and taking the medication; it’s difficult on their schedule. They can’t adhere to the medications. They can’t do their follow-ups. So…I don’t know what to say more about them, but what I know is that they’re afraid of stigma and discrimination from their peers.’ (25–29-year-old, male)
HIV testing challenges	‘They take a long time to test, most of them. They take a very long time to test. You have to emphasize every time when they come for the visit, ‘you should check because this TB is related to HIV.’ So, the more you talk to them, the more they will end up testing, but [only] after a very long time. They don’t just go immediately after diagnosis with TB.’ (30–34-year-old, female)
HIV disclosure and care	‘There was one who tested HIV-positive; her father was taking ARV treatment. The father is always sending the girl to collect supply for the father. So, then this daughter tested positive. The way the father loved her, even the siblings loved her. She was telling me, ‘I can’t disclose my HIV status now because the way they love me it is going to break them. I can’t tell them. I can’t start the ARVs.’ She came the other time I was telling her, now it has changed, when everyone who is HIV-positive should be enrolled… The greatest fear is she doesn’t want to hurt anyone.’ (25–29-year-old, female)
Adherence challenges	‘If they are not supported at home, normally they don’t take their medication. [So] it’s our responsibility to also to teach the family about TB. Sometimes they don’t understand. Sometimes they feel isolated… because this condition they don’t understand what it involves and what it entails, so they feel isolated. And then sometimes this forces them to stop taking their medication because lack of understanding. It becomes a problem.’ (30–34-year-old, female)
Disengagement or LTFU	‘I have this one [client] on DOT. A 24-year-old. At first, that client was just reluctant to take an HIV test. So we sit him down. We talk. We talk. Although it takes some time, but eventually, he agreed for a test, only to find out that he was HIV-positive. So, after finding out that he was HIV-positive, he just disappeared… But we tried, we called him on a daily basis, we tried to talk to him. …At first, he was just dodging, dodging, dodging, dodging, dodging, but eventually I called him and I talked to him, telling him that (by the way) even if you disappear, it doesn’t mean that the disease will disappear, especially TB. If it’s not treated, it can kill by that alone. He comes and then we talk, we talk, we talk, we talk, eventually, slowly, he just gets on the way. Today, he’s just ok. He’s taking HAART. He’s taking antituberculosis therapy. Just doing well.’ (35–39-year-old, female)
Alcohol abuse	‘Ah, sometimes they will say that, ah, (by the way), this treatment it makes my legs painful so I cannot drink alcohol and all the likes, you see. I think that’s one of the main reasons why they default. Alcohol… Even if we talk to them [some continue to drink alcohol].’ (35–39-year-old, female)
Understaffed or overburdened clinics	‘Yeah, if you’ve got enough staff, that wouldn’t be a problem. [If] today I’m going to go to TB room, only doing TB, that’s going to be the best. But now, if I’m somebody doing everything, so I have to queue a few [patients]. That’s when you find that some people end up going without taking treatment. They come the following day, ‘why didn’t you take treatment?’ ‘Ah, it was a long queue!’ They wanted to make it to work, you see. It’s so long. And then they end up rushing to get to work.’ (30–34-year-old, male)

AYA = adolescent and young adult; TB = tuberculosis; HIV = human immunodeficiency virus; HCW = healthcare worker; ARV = antiretroviral; ART = antiretroviral therapy; DOT = directly observed therapy; HAART = highly-active antiretroviral therapy.

Table 3

HCW approaches to AYA TB and TB-HIV care: themes emerging from interviews with HCWs

Major themes	Example excerpts
Adapting visit times	'They don't like waiting. …They'll miss the appointments. You have to follow them. …You have to call them and sometimes you have to accommodate them with awkward hours. …because maybe sometimes when you say come in the morning, they will say, 'no, in the morning we are at school, so we'll come in the afternoon,' or maybe, 'I'm at work, let me come at lunch hour'. You know, it's your lunch hour, but you have to help her. … If she says she'll come at half one, when you are on lunch, you have to make sure that at half one, you see her or you don't see her, you won't see her easily. …Now, it becomes a problem because when the other [HCW] is in now, she won't accommodate that. …And the other nurses now will feel no that's not good, because you are teaching them wrong. But, you are trying to accommodate them. Because, TB we know akare ('isn't it') if you don't accommodate some things, it's communicable. Yeah, if somebody's smear-positive, you want her or him to take treatment properly. Because you know if she doesn't, she can infect you. That's when, sometimes, we have to try to accommodate certain things, which becomes a challenge between you, the client, you, and the staff. The staff is pulling that side; the client is pulling that side.' (30–34-year-old, male)
More intensive education, counseling, and adherence support	'With [younger adolescents, it's] critical to monitor them because they are still young. So, if a day elapses without seeing them, I have to make sure I know where they are, [where and when they've taken their medicines]… That is, the monitoring is much more intense compared to [adults]… there has to be a special way of doing it.' (30–34-year-old, male)
	'To work with TB patients, there are some challenges here and there, but it needs patience. You have to be patient with those patients… you have to listen to their problems, so that we address them, or otherwise they're going to [become LTFU]. [Because] all the patient, so not necessarily this age. …Especially TB patients, because TB is a communicable disease, and you have to be very, very careful when dealing with patients with a communicable disease, because if they [become LTFU], they are going to infect other patients outside. So, we have to be very patient, very supportive and we have to listen to those patients, otherwise you won't succeed.' (25–29-year-old, female)
Youth-friendly services	'We try to be more friendly, as if we are doing youth-friendly services. Of course we don't have [these] here, but we try to, when we are dealing with them, to use aspects of youth-friendly services so that they become more open and more relaxed. At first, some of them are not open. But as time goes on, they become open. But, it just depends on how you talk to them.' (35–39-year-old, female)
Home visits	'I think things like home visits, they can help. But normally when it comes to us nurses, we have a lot to do, but I think NGOs like [local NGO], they're doing a good job by stepping in where we can't manage by assisting us where possible.' (25–29-year-old, female)
	'Normally, we have contacts like their phone numbers, the physical address, where they stay. So normally we follow them at home if [they're] not answering the phone or what. Normally we follow them. The other one was later [found to] be the most MDR-TB. I think he was somewhere between those ages 20–24.' (30–34-year-old, male)
Family as treatment partners	'The [patient] with HIV and TB, the parents were late (deceased). Gore ['because'], he was with the aunt. The aunt she was supportive. She'd always bring him to the clinic until when he coped well. That's when she could let him come alone. She was supportive.' (30–34-year-old, female)
Adapting communication and education to adolescents	'[Our counseling] is different [with AYA] because their level of understanding is not the same. So, along the treatment you just give them enough information they can consume. Like, a 10-year-old, they won't understand a lot of things as compared to a 24-year-old. So you tell them little by little until the time they can just comprehend, accept everything, understand everything about the treatment. But, mostly, these young ones, even if you tell them, you have to educate the [caregiver] because they don't understand that much.' (25–29-year-old, female)
	'In Setswana… if you talk to that [AYA] patient, you can't use the proverbs because they don't even know the meaning of that. You can't use the Setswana which is 'deep.' So you have to make sure that you use the 'light Setswana' – Setswana mixed with English – so that you can be clear. The older [adults], they're going to need Setswana which is 'deep' so that they understand.' (25–29-year-old, female)
Relationship-building with AYA to reinforce care	'They don't want to be seen as TB patients. [Because] to them, being a TB patient is like they have sinned or something. They do know that TB is curable, but the fact that they have TB is difficult for them. So stigma is one of the challenges that we have. So, for you to avoid this stigma you have to build a relationship with your patients so that they can talk there. They can tell you their experiences, challenges so that we address them. Because, if we have this patient, they have the challenges but if you don't address the challenges, they end up [LTFU].' (25–29-year-old, female)
Use of mobile texting or applications	'If you establish a very, very good rapport, you make sure they understand you, you understand them, and you try to use a communication means that is suitable for them. I think that's when you can manage to deal with them. Like, usually, what I do with my clients, they will have my number. Then, there'sWhatsApp, there's Facebook, you will find that some of them, initially, they were uncomfortable with communicating with me face-to-face. But, some they ended up searching me onWhatsApp. They found me onWhatsApp. That is when they started to communicate with me, not face-to-face. …But, when they came now, they said, 'ok, this one, we can easily communicate with him'. But, it's very easy to communicate with him, even face-to-face now. With WhatsApp, I think one of them used because initially I felt she was uncomfortable because she could not ask certain questions when we are together. But, after communicating on WhatsApp, that's when I read as, ok, maybe this one was not comfortable with asking

Major themes	Example excerpts
	me face-to-face. That's maybe why she decided to use other means of communications, but, after that, I think everything went just smooth. We started communicating face-to-face again.' (30–34-year-old, male)
	'Even me, sometimes, you know, I'll struggle to strategize on how to communicate with them… I've realized that giving them my personal number, maybe try to bridge the gap between me and them because wherever they are, if they encounter any problem, it's easy to send an SMS, it's easy to call. Then, if I'm around, I will help. If I'm not around, I will try to find out how best can I advise them to do. That's how I've managed to do my things.' (30–34-year-old, male)
Community-based DOT for AYA with reliable support	'When it's [facility-based] DOT, normally they can just skip for a day. But when somebody at home can give treatment [under community-based DOT], you find that there is no problem. Because when they come back for check-up or for medications, they normally come with those people who are supporting them at home or at work. They will be telling us yeah they're taking treatment ok. But when they're just alone coming here, it's a problem.' (30–34-year-old, male)
Facility-based DOT for AYA with limited support, complications, or failure of community-based DOT	'The clients who [have drug] side effects, we usually have them [in facility-based DOT] until we are very sure that now they're fine. That's when we can give them out [to community-based DOT]. But usually, those getting the injectables, those MDRs if they're there, those are the ones that we want them to come this side so that we ensure that we give them their daily dose including the injection. So those ones, really they have to come this side. But usually after finishing 60 days of the injection, we usually discharge them [to community-based DOT].' (40–44-year-old, female)
Current resources for financial or nutritional support	'We can give them food on that side, and even refer them to social workers for food basket while they're still on treatment. It depends. But it's not that much.' (30–34-year-old, female)

HCW = healthcare worker; AYA = adolescent and young adult; TB = tuberculosis; HIV = human immunodeficiency virus; LTFU = lost to follow-up; NGO = nongovernmental organization; MDR-TB = multidrug-resistant tuberculosis; DOT = directly observed therapy.

Table 4

Interventions required to support AYA TB and TB-HIV care: themes emerging from interviews with HCW

Major themes	Example excerpts
Staffing overburdened clinics	'I think if we had enough transport, maybe we could just go check on them. And, again, the issue of workload… Sometimes, the staffing in a hospital or clinic setting doesn't allow that one can go do some things.' (25–29-year-old, female)
Transportation needed for home visits	'Even the treatment, if they're telling you, 'I can't come in the morning to take treatment,' DOT, maybe every morning if there was transport, you go and give them the supply.' (25–29-year-old, female)
	'Visiting the patients I think is very important, but the problem is the car… I think going to the patient's home, it helps you see what kind of state your patient's living in and what can be improved. Like, maybe the cleanliness, you can talk to them about the cleanliness. And how many people are staying there. Teach them about TB. Because here, you're just exposed to the person who already has TB and you are not helping others next to that particular person.' (35–39-year-old, female)
Strengthened community-based DOT	'[Community-based DOT] is the thing, but that one is a tricky thing. It's not working sometimes. We have community nurses they usually do the home visits to their clients. Yeah, they take the medication there. They do a follow-up. They give the injectables at home. They give medications at home. They come with the transport, like almost every day, once in a week, or twice in a week, they do so. But, the problem we have for now, we have a shortage of manpower and transport.' (25–29-year-old, male)
Peer support	'I think [there is TB stigma], but we try to teach our patients that everyone is at risk for TB. I think when they leave this room, or after they complete treatment, they are different people unlike when they came, with the knowledge they've acquired about TB, and I think they can be the best teachers for others.' (35–39-year-old, female)
	'I think if there were some groups, maybe in the community, it could be a drama group or whatever, o a bona. But just support groups… With some peers, like they're doing with HIV. …There's [lists multiple teen support groups for HIV] and all the like. But with TB, there are no such things… Even if you don't have many adolescents on TB treatment, I think those groups can help. Because, when [the groups are] there, I think more will be coming for testing for TB, for screening. Unlike now.' (35–39-year-old, female)
	'We can have peer educators. By peer educators I mean somebody who has previously been treated for TB and then can lead by example. We can have support groups, and go around in the community teaching about TB. We can sometimes hold some entertainment about TB, like we can have Mr. And Miss TB. We can organize that so that we try to eliminate that stigma and discrimination in TB. Yeah, support groups like the peer educators, counseling, involving the social worker, everything.' (25–29-year-old, male)
More intensive counseling and support	'You have to have continuous education. You just don't stop, because after that, you know the problem with us, the health workers – the initial phase when someone get this HIV, we counsel them – post that, that's the end. And then they start their medication, no counseling, we don't follow up in the counseling, how are they coping, we just don't do that.' (30–34-year-old, female)
Youth-friendly clinics or spaces	'[AYA] can just be maybe have their own clinic where they can receive everything: counseling, pills, checkups, everything. Receive all the health education [and healthcare] … at one place at that time. [These clinics should include peer support.]….So, when a child sees another child going through the same thing, they can understand better that it's not the end of the world. So, I see that as an advantage if they can just have their own clinic.' (25–29-year-old, female)
	'I think there should just be a day where they come alone, not with adults, just them alone, being reviewed by a doctor alone. It's important because they would be free to share with you anything. They'll be free to share with you anything and they won't feel any stigma. When they are just them alone, they'll share among themselves the challenges and how best they can take their treatment.' (25–29-year-old, female)
Youth-friendly education and counseling	'Even when they come here our approach we'll become so nice, we are so interested in them, on one-onone, 'how are you doing?' Finding out about the family, even the relatives. You include them in this health setting. You include them. You find out 'how is this person? How, do you think this person is coping?' These are some of the questions that you can really try to ask, if they come with their parents. You become, you interact with them. That's a careworker. Especially them, one-on-one's, you make everything very colorful.' (30–34-year-old, female)
Airtime or mobile phone for communicating with AYA	'The only resource that I'm using is my airtime. …I'm using my airtime to communicate with them because I cannot call with [the office landline]. If you ask if I was to have a cell phone to call from the government, then that I would say ok, the communication is effective, I'm using the government resource, but the communication part is becoming effective. But I'm using my own airtime. Because me, I think communication, that is the most important thing.' (30–34-year-old, male)
	'We call them when they don't come for treatment… Most of the time you find us using our cell phones to call the clients, which is a problem.' (30–34-year-old, male)
Financial or nutrition support	'They have to work also so they can put food and table at home. So maybe [the government] can help them, those on treatment… When they're taking treatment, maybe it's better for them to have something, maybe a weekly allowance. So that can help them somehow. That's what I'm thinking.' (30–34-year-old, male)

Major themes	Example excerpts
	‘Maybe if we had a garden there to give them some vegetables… Most of them will complain of not having enough food. That’s why it could be helpful to them.’ (30–34-year-old, female)
Addressing alcohol abuse in AYA	‘Some of them [drink]. Even if we talk to them, they do. You see. … But some of them, they just stop when you tell them, but some they just continue. So you don’t know if either is it difficult or they just don’t want to.’ (35–39-year-old, female)

AYA = adolescent and young adult; TB = tuberculosis; HIV = human immunodeficiency virus; HCW = healthcare worker; ART = antiretroviral therapy; DOT = directly observed therapy.

Table 5

Potential areas for further investigation or implementation to support AYA TB or TB-HIV care

Intervention	Rationale and supporting data from this study
National or international guidelines for AYA TB care	• HCW recognize a need to adapt TB care for AYA, yet currently no national or international guidelines provide guidance to address AYA-specific challenges or provide youth-friendly services in TB care
HCW training for providing TB and TB-HIV care to AYA	• Differences of communication in adolescents • Need for more intensive counseling for TB education and adherence • Need to better integrate TB and HIV testing and care, which may be better facilitated by HCW training in integrated care
Youth-friendly spaces	• HCW perceive that AYA desire to receive TB care and other health services separately from adults and that they would be more encouraged to access care in a youth-friendly space
Peer support	• Broad HCW interest in and support for implementing peer mentorship or peer groups for AYA TB treatment
Resources for home visits	• Home visits allow for tracing of absent or LTFU AYA and evaluation of the home/family situation, including contact-tracing
Clinic navigator	• Adolescent needs to attend school or work; mobility and migration; and difficulties navigating and sustaining TB care • Potential for clinic navigator role to help AYA better understand and navigate the health system to access TB and TB-HIV care
Mental health and alcohol abuse interventions	• HCW perceive important mental health challenges and need for psychologist support • Alcohol abuse is seen as a barrier to TB care, yet HCW report having little guidance or support in managing AYA with TB and alcohol abuse
Mobile technology interventions	• Adolescent mobility and communication differences; willingness to communicate challenges through messaging apps; facilitation of relationship with HCW or potentially with peer mentors • Potential for messaging applications or social media to facilitate AYA TB care or education • Potential for video-observed therapy over mobile applications

AYA = adolescent and young adult; TB = tuberculosis; HIV = human immunodeficiency virus; HCW = healthcare worker; LTFU = lost to follow-up.